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ABSTRACT

This paper explains recent changes in the Supplemental Security Income (SSI) program that affect adolescents with disabilities or chronic health problems. Changes include the SSI work incentives available to them, how they can maintain access to quality health care and benefits during their transition years, and key issues in transition planning. The first section is on maintaining health care and benefits and summarizes regulations concerning changes in SSI eligibility criteria, continued Medicaid eligibility, and the new Children's Health Insurance Program. The second section addresses SSI work incentives for adolescents and young adults. These include the Plan for Achieving Self Support (PASS) program, continuation of SSI eligibility despite earnings above the "substantial gainful activity" level, continuation of Medicaid eligibility after SSI eligibility is lost, impairment related work expenses, the student earned income exclusion, and transition planning opportunity points (ages 14, 16, 18, 21, and 22). The final section identifies key issues, especially the need to ensure access to health care, job training or higher education, services and supports needed to participate in the competitive job market, and income, either from disability benefits or a combination of job income and disability benefits. Other issues address rehabilitation services, service coordination, and improving work incentives. (DB)

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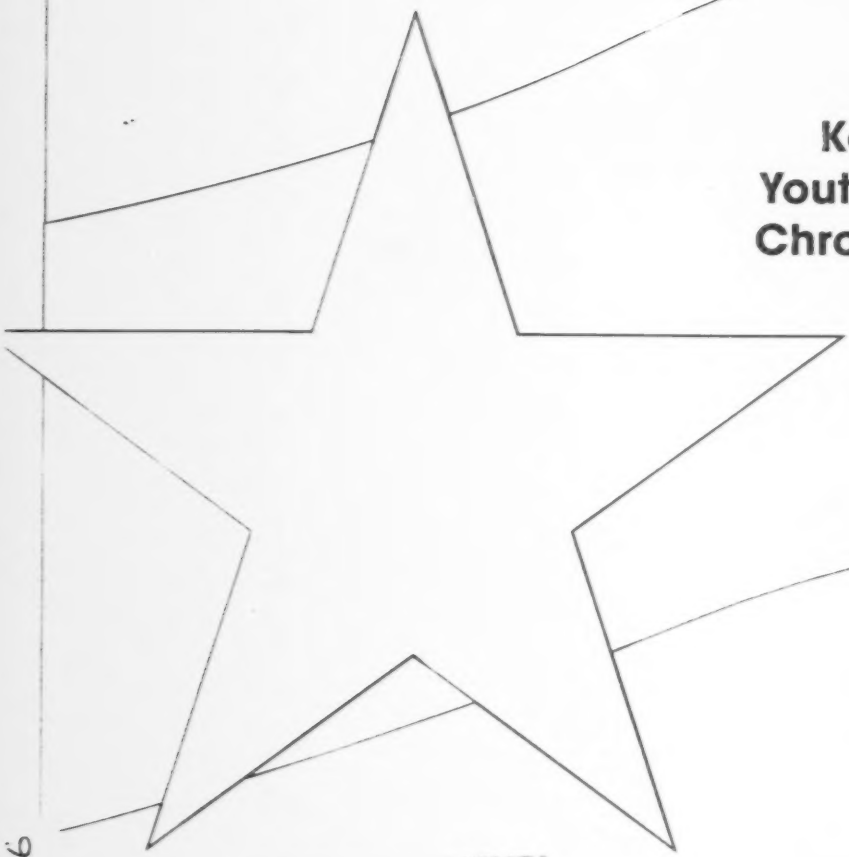

Key Transition Issues for Youth with Disabilities and Chronic Health Conditions

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Promoting a comprehensive system of family-centered, culturally competent, community-based care for children with special health care needs who are approaching adulthood and may need assistance in making the transition from pediatric to adult health care and to post-secondary education and/or employment.

Healthy & Ready to Work (HRTW) is an initiative of the Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).

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Key Transition Issues for Youth with Disabilities and Chronic Health Conditions

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Introduction

Title V of the Social Security Act, also known as the Maternal and Child Health Services Block Grant, provides federal funds that states can use to ensure access to quality maternal and child health services. Administered by the Maternal and Child Health Bureau [MCHB], state Title V programs help build family-centered, community-based systems of care for all mothers and children, including those with chronic illnesses and disabilities.

http://www.mchb.hrsa.gov
http://cshcnleaders.ichp.edu

MCHB's Healthy & Ready to Work [HRTW] initiative aims to address special issues facing adolescents with chronic health conditions and disabilities who are preparing to make the transition from school to work and greater independence. Although there is significant concern about the importance of coordinating community systems of comprehensive services for infants and children, the needs of adolescents more frequently are overlooked. Through its initiative, MCHB aims to help develop family-centered, culturally competent systems of care for this population of adolescents. The Bureau also wants to assure that the health-related issues faced by adolescents during transition are addressed appropriately.

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The initiative is particularly timely because recent changes in federal and state education, health, and social services programs pose new challenges for policymakers, service providers, and families. For example, major changes in the Supplemental Security Income [SSI] program and the special education law affect the ability of adolescents to access health care and support services. As they begin to plan how to obtain the educational and job training services, financial support, health insurance, and community supports they need to achieve their maximum levels of independence, young people must understand both the implication of these changes and that having access to health care and being healthy are critical components of being employable.

This paper describes recent changes in the SSI program affecting adolescents, what SSI work incentives are available to them, how they can maintain access to quality health care and benefits during their transition years, and key issues to consider during transition planning. It is the first of a series of working papers aimed at assisting service providers and families to ensure successful transitions to work and independence for youth with disabilities and chronic illnesses.

Maintaining Health Care and Benefits

Impact of SSI Eligibility Changes for Adolescents and Young Adults

The Supplemental Security Income [SSI] program provides monthly cash assistance to eligible children and adults who are disabled or blind. Although Congress enacted the SSI program in 1972, relatively few children received benefits until the 1990 landmark U.S. Supreme Court case, *Sullivan v. Zebley (493 US 521)*. Prior to *Zebley*, a child could qualify only if he/she had specific medical impairments and the impact of these conditions on the child's ability to function was not considered. As a result of the *Zebley* decision, the Social Security Administration [SSA] revised its eligibility rules to provide an "individualized functional assessment" [IFA] of a child's overall limitations. Around the same time, SSA also issued new rules to evaluate children with mental impairments. After these eligibility changes, enrollment in the program grew dramatically from an enrollment of about 438,000 children in December 1991 to about 1 million by June 1996. SSA data indicate that by that time, more than one-fourth of the eligible children were 14-18 years old.

The full text of the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (P.L.104-193) and the interim final regulations for childhood disability are both on the Internet at http://www.ssa.gov/odhome under "Welfare Reform and Childhood Disability."

The growth in program enrollment prompted serious concerns among the public and legislators about the eligibility criteria, especially for children with emotional and behavioral problems. A few very visible media stories about families allegedly abusing SSI benefits created a perception of rampant abuse despite findings by several studies that there was no proof of widespread program fraud. However, as public confidence eroded, policymakers began to question the program's purpose and value, opening the door for Congress to enact major changes in the childhood disability program in its welfare law, the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 [P.L. 104-193]. While some adolescents may continue to receive SSI benefits, others will lose eligibility because of these major SSI program changes.

Interim final regulations, issued on February 11, 1997, immediately implemented the following changes affecting the current and future eligibility of adolescents and young adults.

The SSA Listing of Impairments is published in Disability Evaluation Under Social Security, generally called "the Blue Book" (1/98: SSA Publication No. 64-039). For a free copy FAX a request to 410/965-0696 or write: SSA, Office of Communications, Public Information Distribution Center, PO Box 17743, Baltimore, MD 21235.

1. **A child must have physical or mental impairments causing "marked and severe functional limitations" under a new definition of childhood disability.**

Children now have to meet a new higher standard of disability to qualify for SSI benefits. They must demonstrate that they "meet or equal a listing," that is that their medical impairment matches, or is medically or functionally equivalent to, a listed condition in SSA's Listing of Impairments.

To begin implementing this new higher standard, Congress required SSA to review the eligibility of about one-third of the total children's SSI enrollment to ensure that they still qualify. As of May 30, 1998, almost 93 percent of the required redeterminations were completed. Data from Social Security show that 147,575 (60.1 percent) of the 245,349 children redetermined at the initial level lost their SSI benefits. The impact of the redeterminations was particularly significant for children over the age of 12. Of children ages 12-15, 63 percent (53,726) lost their benefits; among children ages 16-17, 72.7 percent (25,525) lost their benefits; overall, children over age 12 represent 56 percent (79,251) of all recent terminations.

Appeal data by age are not available. However, the SSA data show that among the 53,151 cases reviewed on appeal, 21,835 children had benefits continued at the first level of the appeals process ("reconsideration"). This represents a 41 percent reversal rate of the initial eligibility decision. As historically, the reversal rate has not been this high at the reconsideration stage, it is very important to encourage families to appeal any termination of benefits because there is a good chance of regaining eligibility.

The loss of SSI benefits has serious implications for children who may also lose their Medicaid coverage. Under the Balanced Budget Act of 1997 [P.L. 105-33], children whose cash benefits stopped after a redetermination under the new SSI eligibility rules are entitled to keep their Medicaid. As problems have been reported, it is advisable to check with families to ensure that children who lose SSI benefits are able to retain their Medicaid. [See page 7 for a fuller discussion of what happens to their Medicaid coverage when children lose SSI eligibility.]

2. A child will no longer be evaluated under an "individualized functional assessment" as part of the disability evaluation process.

Although the functional assessment was eliminated, evidence of a child's functional limitations is still a critical part of the disability evaluation. SSA must consider all relevant evidence from such medical and nonmedical sources as parents, teachers, and others who know the child. When reviewing evidence about the child's impairment(s), SSA uses a three-step sequential evaluation of the child's condition to determine if the impairment is severe enough to qualify by: (1) meeting one of the specific medical impairments on SSA's list of childhood impairments; (2) being "medically equivalent" to a listed impairment; or (3) being "functionally equivalent" to a listed impairment.

Children may qualify with a "functionally equivalent" impairment that causes "marked and severe" limitations in one of four ways: (1) limitations of specific functions; (2) limitations from chronic or episodic impairments; (3) limitations from treatment of effects of medication; or (4) broad functional limitations.

When using one of the first three methods, the disability decisionmaker must identify the specific listing to which the child's impairment(s) is functionally equivalent. When using the fourth method (broad functional limitations), the decisionmaker must consider if the child's impairment(s) causes either an extreme limitation in one area of development or functioning or a marked limitation in two areas. Children are assessed based on their age and ability to function and/or develop in up to five broad areas, depending on their age: cognition/communication, birth-18; motor, birth-18; social, birth-18; personal, 3-18; responsiveness to stimuli, birth-1.

3. **A child must have a continuing disability review [CDR]) once every three years if his/her impairment is likely to improve.**

SSA is required by law to conduct periodic continuing disability reviews [CDR] of whether an adult or child who receives SSI disability benefits is still disabled. If an individual's condition improves so that it no longer meets the eligibility criteria, SSA stops paying benefits. To determine if an individual is "not disabled," SSA uses its "medical improvement" standard to judge if there is any decrease in the medical severity of the impairment(s) that was present at the individual's most recent favorable disability decision. Even when there is proof of medical improvement, however, SSA must decide if the individual is still considered disabled under the SSI eligibility rules by considering all current impairments and any new qualifying impairments.

4. **A child must have evidence at the continuing disability reviews that he/she is receiving treatment that is "medically necessary" and "available" for the disabling condition.**

At the continuing disability review, the child's representative payee must present evidence that the child is receiving treatment that is "medically necessary" and "available" for the disabling impairment. The regulations define "medically necessary" as treatment that is expected to improve or restore the child's functioning, but not necessarily to the point of nondisability. The required degree of improvement is not specified in the regulations. The treatment must be prescribed by a treating source and if the child does not have one, SSA will decide whether there is medically necessary treatment that could have been prescribed.

Treatment may include, but is not limited to: medical management; psychiatric, psychological or psychosocial counseling; physical therapy; and home therapy, such as administering oxygen or giving injections. Factors considered in evaluating if medically necessary treatment is available and if the payee had "good cause" for failing to obtain it for the child are:

- location of institutions or facilities that could provide treatment;
- availability and cost of transportation to such places;
- health, including the child's ability to travel for the treatment;
- capacity of an institution or facility to accept the child for treatment;
- cost of treatments not covered by Medicaid or another insurer; and
- availability of local community resources that could provide free treatment.

5. A child turning age 18 must have his/her eligibility redetermined by SSA under adult eligibility rules.

SSA must redetermine the disability eligibility of individuals in the month before they become 18 years old. Data from SSA show that by May 30, 1998, there were 61,402 reviews of this age group and 56.7 percent (34,803) had lost benefits. The appeals data indicate that among the 10,732 cases reviewed, another 3,711 received continued benefits. This 35 percent reversal rate of the initial denials illustrates the importance of appealing. However, even with successful appeals, only one-half of the young people are remaining eligible for SSI, raising serious concerns about the ability of those losing benefits to plan a successful transition and ensure continued health care coverage.

The law requires SSA to apply the adult eligibility criteria when redetermining if individuals at age 18 still qualify. Qualifying for SSI through a new determination of eligibility is more difficult than maintaining eligibility through the protection of the medical improvement review standard used in continuing disability reviews.

6. A child receiving past-due SSI benefits totaling more than six times the maximum monthly benefit must put the funds into a dedicated savings account that may be used only for certain expenses.

The law now requires SSA to place the entire past-due amount into a dedicated account when children receive large retroactive payments. This situation arises if the application process takes a long time, resulting in one large payment of benefits when the child is found eligible as SSA pays benefits from the application date. Dedicated accounts — required when the child's SSI benefits total more than six times the maximum monthly benefit — may be used only for certain expenses related to the child's disability.

Basic costs for food, shelter, clothing, and personal items generally cannot be paid with dedicated account funds unless the expenditures are related to the child's impairment. However, in emergency situations, a child may use these funds for basic costs when the parent or representative payee shows that "homelessness and/or hunger is imminent."

The restrictions for the dedicated accounts are a significant departure from SSA's traditional rules regarding the use of benefits. Funds in a dedicated account may be used only for medical treatment and education or job skills training. Other allowable expenses, provided they are related to the child's impairment, include: personal needs assistance, special equipment, house modifications, therapy or rehabilitation, and other items or services SSA determines appropriate.

These other items or services must help the child overcome the limitations of the disability or reduce symptoms or remediate developmental impairments. Examples of allowable expenses that could be related to the child's impairment include:

- household furnishings and appliances and changes in utility services (e.g., air conditioning, washing machine, telephone installation);
- housing renovations (e.g., home insulation, separate bedroom);
- special play and recreation equipment;
- special foods;
- special clothes (e.g., orthopedic shoes);
- personal aids (e.g., assistive technology, modified instructional materials);
- computers and related accessories and software (e.g., needed for vocational training or educational program);
- transportation costs to training classes, therapy sessions (e.g., bus or cab fare or, in some cases, purchase of vehicle);
- increased electric costs due to impairment-related mechanical devices;
- specialized day care and therapeutic recreation (e.g., special summer camps or Special Olympics);

- repair of walls, carpets, or furnishings damaged by child with disability;
- counseling, crisis intervention services, respite care, or therapeutic foster care if not covered by public or private health insurance;
- repayment of past debt;
- attorney fees related to child's disability claim.

The representative payee must explain to SSA how the requested item or service will improve or treat the child's condition or is related to the impairment. However, SSA personnel are instructed to consider all requests carefully and, before denying a request, must ensure that the representative payee has the opportunity to explain or provide supporting evidence why or how the expenditure relates to the child's impairment. Denials of proposed expenditures are considered an "initial determination" and can be appealed. SSA is developing instructions and notices to implement this procedural change.

Continued Medicaid Eligibility

The Balanced Budget Act (P.L. 105-33), passed in August 1997, requires Medicaid coverage to continue for children if their SSI benefits stop after an eligibility redetermination under the new definition of disability. Section 4913 of this law allows children who were receiving SSI payments on August 22, 1996 (the effective date of the welfare law), but who no longer qualify under the new SSI rules, to continue their Medicaid eligibility.

A summary of the provisions from the Balanced Budget Act of 1997 that affect SSI eligibility for children is available on the Internet: http://www.ssa.gov/odhome under "Welfare Reform and Childhood Disability."

The Health Care Financing Administration [HCFA] explained the legal requirement to continue Medicaid for these children in a November 13, 1997 letter to states. The letter emphasized that states may not remove these children from the Medicaid program and that it is illegal to terminate their Medicaid coverage and suggest that families have to reapply.

See HCFA's website: http://www.hcfa.gov/Medicaid/bbakids.htm for the text of the letter on Medicaid.

There is no similar protection for children who lose SSI eligibility for nondisability reasons (e.g., they no longer qualify financially) so they may lose their Medicaid. However, before terminating someone's eligibility, the state Medicaid agency is required to make a new (an *ex parte*) redetermination under all other eligibility categories. In every state, there are mandatory groups of individuals who qualify for Medicaid, but each state can also select optional eligibility groups to cover. Child-serving professionals who work with adolescents with special health care needs and their families should be familiar with both the mandatory and optional Medicaid-eligibility categories in their state.

The purpose of the mandated Medicaid redetermination is to assure that medical assistance continues until a final decision is made regarding the individual's eligibility. The federal law places the responsibility on the state Medicaid agency — not on the child or family — to initiate the review process. The Medicaid redetermination can be based on information in the child's file, but the state agency may contact the family if additional or updated information is needed. The Medicaid agency must notify the family promptly about its decision and, if the child is not eligible, it must explain the right to appeal the termination.

New Children's Health Insurance Program

Another option for adolescents and young adults through age 18 with chronic health conditions and disabilities to consider is the new Children's Health Insurance Program [CHIP], Title XXI of the Social Security Act. Enacted in 1997, CHIP has the potential to provide health care for millions of uninsured children. The program will provide $4 billion a year for 10 years in grants to states to cover uninsured children with family incomes too high for Medicaid but too low to afford private insurance. States can use CHIP funds to expand Medicaid coverage, develop a separate state program, or combine the two approaches. The benefits and eligibility criteria vary significantly from state to state.

See http://www.hcfa.gov for status of state CHIP plans and state contacts.

As of September 1998, 48 jurisdictions (45 States, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands have submitted child health plans, and HCFA has approved 34 plans. An initial review of these plans shows that most will cover young people through age 18. Every month more states are approving plans, so this is an area to watch closely.

For AAP fact sheets, see their web site: www.aap.org/member/factsnew.htm or for more detailed information see: www.aap.org on their SCHIP web page.

The American Academy of Pediatrics [AAP] has compiled State-specific children's health insurance fact sheets for each of the fifty states and the District of Columbia that include annual expenditure per Medicaid participant for 1996, current and potential income eligibility for public programs, and program eligibility for uninsured children.

SSI Work Incentives for Adolescents and Young Adults

SSA has several work incentive programs to help people with disabilities enter or re-enter the workforce. Although most of these programs are designed for adults, some may help older children and adolescents who want to work or pursue vocational or educational goals. Work incentives are available to people receiving SSI or Social Security Disability Insurance [SSDI, generally called "Social Security," disability or Title II] benefits. [Children with disabilities may be eligible for Social Security/Title II benefits. This paper, however, discusses only work incentives available through the SSI program.]

For more information on the Social Security/Title II work incentives, check on the Internet: http://www.ssa.gov for the benefit publications.

Work incentives can, in theory, provide a way for young adults and adolescents to enter the job market. However, the work incentives rarely are used by SSI beneficiaries. Their reluctance to use work incentives is not really surprising given the consequences — losing cash benefits and medical coverage and, quite likely, facing unstable employment prospects. It can be very difficult for people with disabilities to find jobs with a salary and health coverage that duplicate the cash and medical benefits received through the SSI program.

Further, the work incentive programs are complex and difficult to understand. Despite intense efforts by SSA and other organizations to publicize and educate adults and families about these benefits, they are used by only a small fraction of those who are eligible. Also, the work incentives are very expensive for SSA to administer and too frequently result in benefit overpayments that must be returned.

Recognizing the need to increase work force participation among individuals with disabilities, SSA and Congress are now considering different ways to improve the work incentives.

The Institute for Child Health Policy will provide updates at: info@ichp.edu or see: http://www.ichp.edu which will explain legislative or policy changes that may encourage wider use of these programs by adolescents and young adults.

Despite concerns about work incentive programs, they can allow SSI beneficiaries to:

- deduct certain expenses related to employment;
- set aside money for future expenses;
- continue to receive cash benefits when their earnings exceed the substantial gainful activity [SGA] level; and
- continue to receive Medicaid as earnings increase beyond a certain income threshold.

The SSI regulations are found in Volume 20 of the Code of Federal Regulations (C.F.R.). Individual C.F.R. volumes are available from U.S. Government bookstores, in most law libraries and courthouses, and through the Internet: http://www.law.house.gov/cfr.htm. C.F.R. citations are provided for each work incentive discussed.

The SSI work incentive programs are designed to help people with disabilities have income from a job while they reduce their reliance on cash benefits. When applying for SSI benefits, an individual must meet certain financial and disability requirements. To establish the required level of disability, SSI applicants must show that they are either unemployed or if working, earning below the "substantial gainful activity" [SGA] level. This SGA level, which generally is less than $500 a month in gross earnings, is an important part of the SSA determination of the amount of the SSI check for someone who is working and receiving benefits at the same time.

The work incentive provisions, which are part of the Social Security law, are implemented through regulations.

Plan for Achieving Self Support (PASS)

The Plan for Achieving Self Support [PASS] allows an individual to exclude income and/or resources that SSA would otherwise count when determining SSI eligibility. When used under the approved plan, the money set aside in a PASS will not be counted by the SSI program. Using a PASS, someone can become eligible as a new SSI applicant. A current SSI beneficiary can use a PASS to maintain eligibility despite increased income or resources or to receive a larger benefit.

The PASS is a written plan that must be approved by SSA. Local Social Security offices can provide the PASS form, SSA-545-BK, which collects most of the information that SSA needs to review someone's plan. The completed forms are reviewed by specially trained SSA employees, and if changes are needed, the PASS expert contacts the applicant to discuss them. If the PASS is not approved, applicants can appeal the denial through the regular SSA appeals process.

The PASS requires very specific information, including both a realistic work goal and the intended job or profession that the applicant wants to pursue. The PASS also must describe a timetable with specific steps for reaching the work goal and the amount of money and resources that will be saved to reach the goal.

Among the items that can be funded through a PASS are: vocational services including job development, job placement services, vocational evaluations, and job coaching; basic living skills or training related to the work goal; personal assistance care; costs associated with an educational or occupational training program, including room and board, tuition, books, and supplies; transportation costs, including lease, rental, or purchase of a vehicle; assistive technology and work site modifications; or the costs associated with starting a business.

When helping a young person decide if he/she is a likely candidate for a PASS, several factors should be considered. First, does the student have a specific job goal? Given this requirement, it is sometimes difficult for high school students to use a PASS to begin to save for services they may need after graduating. Second, does the student have income or resources that can be set aside for a PASS? The plan allows individuals to set aside otherwise countable income and/or resources to qualify financially for SSI or to receive a bigger SSI check. As SSI payments cannot be set aside for a PASS, in certain families there is no extra money to save. Nevertheless, PASS can be an important source of funding for educational or vocational services for students who have the ability to plan and save for the future.

Over the past few years, major changes were made in rules which have confused individuals trying to apply for a PASS. There are several sources of current information [see sidebar column at right] about PASS.

For the PASS legal authority, see 20 C.F.R. Section 416.1180.

PASS regulations have less information than the Program Operations Manual System (POMS) (used by local SSA offices and disability determination services staff). Local SSA offices are required to allow public access to POMS, which has detailed guidelines for processing and deciding SSI applications, at SIE00870.000 and at http://www.ssa.gov/odhome, along with a 12/1/1997 description of changes to improve PASS policies, procedures, applications and reviews.

"Help us get the word out" from Susan Daniels, SSA Deputy Commissioner for Disability and Income Security Programs: http://www.ichp.edu/ssi, describes letters mailed 4/30, to individuals whose PASS was terminated or denied 4/1/96-11/30/97 when the rules changed.

Continuation of SSI Eligibility- Section 1619(a) of the Social Security Act

Individuals can receive SSI benefits even if they earn above SGA as long as they continue to meet all other SSI eligibility requirements. This allows individuals to begin working and still maintain eligibility for cash benefits up to a certain income limit. Cash benefits are calculated the same way as for someone who is not working so individuals' amount of their SSI payment are reduced as their earnings increase. Once their income exceeds the SSI limits, all cash benefits stop. Individuals who are eligible for 1619 (a) receive both cash benefits and Medicaid.

Continuation of Medicaid Eligibility- Section 1619(b) of the Social Security Act

For the legal authority, see 20 C.F.R. Section 416. 260-416.269.

Individuals whose earnings become too high for cash payments can still get Medicaid coverage after their SSI benefits stop. To be eligible, individuals must still have a disabling impairment, need Medicaid coverage to work, earn gross income at levels that are insufficient to replace Medicaid with private insurance, and continue to meet the financial criteria of the SSI program. Medicaid will continue until their earnings reach a threshold calculated to reflect the value of SSI, Medicaid (based on the state's average expenditure per person), and the value of any publicly-financed personal care assistance. The earnings thresholds vary by state, but generally range from $15,000-$24,000. Individuals who can document that their medical needs are higher than average can establish an "individualized threshold" based on their own expenses.

Impairment Related Work Expenses (IRWE)

For the legal authority, see 20 C.F.R. Section 416. 260-416.269.

Certain impairment-related items and services needed to work can be deducted from gross monthly earnings. Deducting these costs can reduce counted earnings below SGA ($500), help maintain program eligibility, and increase monthly SSI cash benefits. Expenses qualify as an IRWE if they enable the individual to work, are paid for by the individual, are not reimbursable by private or public sources, and have a reasonable cost. The items and services must be needed because of the impairment and required to perform the job.

The SSA local office decides whether items can be deducted as IRWEs. Examples include:

- adaptive equipment or special devices;
- personal assistance to prepare for or travel to work;
- personal assistance to perform personal functions at work;
- prescribed treatment or therapy necessary to control a disabling condition;
- durable medical equipment;
- special transportation;
- job coach services; or
- work-related equipment needed to perform the job.

Student Earned Income (SEI) Exclusion

See 20 C.F.R. Section 416.1112(c)(3) for the legal authority.

Students can exclude up to $400 of earnings a month, but not more than $1,620 in a calendar year. This exclusion reduces the amount of countable income that is used to determine the student's eligibility and benefits. To qualify for the exclusion, the student must be under age 22, not married or a head of a household, and regularly attending a school, college, university, or course of vocational or technical training.

Transition Planning Opportunity Points

Transition planning, the lifelong process of preparing a young person for the future, is far more complex for a young person with a disability or a chronic illness. In general, as young people and their families work with a number of agencies that provide services or supports, the period of transition planning intensifies over the four-to-six-year period after the child turns 12. So that families can access services that are mandated for their children, professionals working with the families need to know what community agencies and resources are available to provide assistance and understand the legal responsibilities of various public agencies. A review of the legal responsibilities of relevant public agencies reveals different "opportunity points" in transition planning when families and professionals need to check to ensure they are utilizing all means to provide access to health care, education, rehabilitation services, and income benefits.

Age 14

- Under the Individuals with Disabilities Education Act [IDEA] Amendments of 1997, schools must now include a "statement of the transition service needs" in a student's individualized education program [IEP] beginning at age 14. This statement, to be updated annually, should focus on how to plan the student's education program through appropriate courses of study (P.L. 105-17, Section 614). This new requirement supplements — and does not replace — the separate transition services requirement that begins for students no later than age 16, [described below].

- Social Security refers SSI-eligible individuals who are under age 16 to the state Title V agency.

  See 20 C.F.R. Section 416.1710.

- State Title V programs are required to provide "rehabilitative services" for children under age 16 who receive SSI to the extent that medical assistance for such services is not provided by Medicaid. The array of services provided vary considerably from state to state.

  See 42 U.S.C.A. Section 701(a)(1)(C)

Age 16

- Under the Individuals with Disabilities Education Act [IDEA] Amendments of 1997, the student's IEP must include a statement of needed transition services, beginning at age 16 or younger [see Age 14, above] if determined appropriate by the IEP team (P.L. 105-17, Section 614). Transition services are defined by the law as a "coordinated set of activities that... promote movement from school to post-school activities, including post-secondary education, vocational training, integrated employment (including supported employment), continuing

and adult education, adult services, independent living or community particpation." The law clearly states that a range of activities are included, such as instruction, related services, community experiences, developing employment and other adult living objectives and, when appropriate, acquiring daily living skills and functional vocational evaluation.

- Social Security refers SSI-eligible individuals to the state vocational rehabilitation agency starting at age 16.

See 20 C.F.R. Section 416.1710.

Age 18

- In the SSI program, SSA no longer counts family income so the financial eligibility of young adults is based only on their own income and resources.

- In the SSI program, SSA uses the adult eligibility rules to decide if an individual qualifies as "disabled." SSI-eligible children must have a new disability determination under the adult eligibility rules in the month before they become 18 years old to determine if they can continue to receive benefits.

- Some state Children with Special Health Care Needs (State Title V) Programs only serve young people under age 18. Eligibility and service criteria vary considerably from state to state.

The 1998 edition of the *Directory of State Title V CSHCN Programs Eligibility Criteria and Scope of Services* is available from the ICHP web site: www.ichp.edu or by sending and email request to info@ichp.edu for disks.

- States may offer health benefits through age 18 using the new Children's Health Insurance Program [CHIP]. States can use CHIP funds to expand Medicaid coverage, develop a separate state program, or combine the two approaches to cover uninsured children with family incomes too high for Medicaid, but too low to afford private insurance.

- Under IDEA, beginning at least one year before students reach the age of majority under state law, their Individualized Education Program [IEP] must contain a statement that they have been informed of their rights under the law that will transfer to them as adults (P.L. 105-17, Section 614). The "age of majority," which varies by state, generally occurs sometime between ages 18 and 21.

Age 21

- Most state Children with Special Health Care Needs (State Title V) Programs serve young people until they reach age 21.

- Early and periodic screening, diagnostic and treatment [EPSDT] services must be provided to Medicaid-eligible individuals until they reach age 21.

Age 22

- Federal law requires that special education services must be available through age 21. Students with disabilities can use this time to acquire skills necessary for independent living or employment. These needs must be stated in the student's IEP and should include opportunities for community-based instruction and other adult objectives. However, some states interpret the law to stop education services at age 18 for special education students who graduate without receiving a regular high school diploma.

- In the SSI program, certain individuals under the age of 22 can use a student earned income [SEI] exclusion when calculating their benefits.

Key Issues

There are many individuals, public agencies, and community organizations across the country working to improve transition opportunities for youth who have disabilities or chronic health conditions. In finding ways to help these young people make a successful transition from school to work and greater independence, a number of issues arise, including the need to ensure access to:

- health care;
- job training or higher education opportunities;
- services and supports needed to participate in the competitive job market; and
- income, either from disability benefits or a combination of job income with disability benefits.

There is a critical need to increase work opportunities for these young people, to ensure their continued access to quality health care and benefits, and to improve coordination and collaboration among the various public agencies that have legal responsibilities to serve them.

Issues in Maintaining Health Care and Related Services during Transition Years

- If children lose SSI after a disability redetermination under the new eligibility rules, was Medicaid continued as required by the Balanced Budget Act of 1997?
- If children lose SSI for nondisability reasons, did the state Medicaid agency review their cases to establish eligibility under another category before terminating their coverage?
- If children are not eligible for Medicaid, is publicly-funded health insurance available through the state's new Children's Health Insurance Program [CHIP]?
- Does the state have any optional categories of Medicaid eligibility that might be available to young people served by the State Title V program who cannot qualify for CHIP because of their age?

- Is the State Title V program providing "rehabilitation services" to SSI-eligible children with disabilities and chronic conditions under the age of 16 when these services are not covered by Medicaid?

Health Care

For families raising children who have special health care needs, the concept of a "medical home" is important. It provides: access to comprehensive, family-centered, culturally competent systems of care to meet the complex needs of children with chronic conditions and disabilities; opportunity for pediatricians and parents to collaborate as partners to identify and obtain all the medical and nonmedical services that children and their families need; and — especially important for this population of children as they become adolescents — access to continuous quality health care. For young people with chronic illnesses and disabilities who may be affected by changing eligibility rules, understanding how to maintain uninterrupted health insurance is critical.

For information about medical homes for children with special needs, check the American Academy of Pediatrics Internet site: http://www.aap.org/advocacy/medhome.htm OR e-mail the Medical Home Program for Children with Special Needs: medical_home@aap.org OR call 800/433-9016, ext. 7081

Some children and adolescents who lose their SSI eligibility under the new disability rules may also lose their Medicaid coverage. Despite instructions from the Health Care Financing Administration [HCFA], states are not uniformly restoring Medicaid for children who lose SSI after their disability redeterminations even though they are protected by provisions in the Balanced Budget Act [see page 7]. There are additional concerns about the loss of Medicaid for young people losing SSI eligibility after newly-mandated continued disability reviews or redeterminations at age 18. Although state Medicaid agencies are required to explore other possible grounds for eligibility before terminating coverage, this does not always occur.

There are both mandatory and optional Medicaid-eligible groups in every state. During the past decade, Congress has enacted certain mandatory Medicaid expansions for low-income pregnant women and children. Under federal law, children from age 6 through 13 with income below 100 percent of the federal poverty level now are eligible for Medicaid. By the year 2002, all poor children under age 19 will be eligible for Medicaid.

States also can select from a number of optional categories for Medicaid coverage, including:

- expanding coverage beyond the federal requirements by accelerating the phase-in eligibility of older poor children before year 2002;
- raising the income limit above that required by the federal law; and
- covering individuals who would be eligible if institutionalized, but who are receiving care under a home- and community-based services waiver.

States also can choose to extend Medicaid eligibility to individuals who are over the income limits for the mandatory or optional categorical groups. This group, called the "medically needy," are allowed to "spend down" to Medicaid eligibility by incurring medical expenses reducing their income to a level below the maximum allowed by the state Medicaid agency. The "medically needy" category includes individuals whose income exceeds the SSI financial criteria but who meet the SSI disability standard and have high medical bills.

The Medicaid law has numerous mandatory and optional eligibility categories and states have considerable flexibility to structure their own programs. Although there are broad federal guidelines, each state has the authority to determine who is eligible and the types, amounts, and duration of the services covered. Consequently, Medicaid varies considerably from state to state although all consider family income and the child's age.

With new money for the Children's Health Insurance Program, states are making additional decisions about how to expand health benefits for uninsured, low-income children which may benefit adolescents under age 19 who have chronic conditions and disabilities. However, there still are major concerns about young people who cannot qualify for CHIP after age 19 and who did not previously qualify for Medicaid. Every effort must be made to determine if they are now eligible under any optional Medicaid eligibility category in their state.

Rehabilitation Services

See 42 U.S.C.A. Section 701(a)(1)(C).

In addition to continuous health care, this population of young people need services that will help maximize their potential. A stated purpose of the Title V Block Grant legislation is to provide rehabilitation services programs to SSI-eligible children under the age of 16 when these services are not available through Medicaid. State Title V programs get referrals of all new SSI beneficiaries under age 16 from SSA under a provision in the Social Security Act.

See 20 C.F.R. Section 416.1710.

The appropriation of federal funds to provide specialized rehabilitative services for children began in 1976 with the creation of the SSI/Disabled Children's Program [SSI/DCP]. States were required to provide medical, social, developmental, and rehabilitative services where such services "reasonably promise to enhance the child's ability to benefit" from education or training. While SSI/DCP funds were provided to purchase services, it was not intended to operate as a new health program but designed primarily to assure a State Title V agency coordinating and integrating role.

In 1981, Title V was significantly amended by the Omnibus Budget Reconciliation Act (Pub. L. No. 97-35) which repealed a number of categorical programs — including SSI/DCP — and consolidated them into the MCH Block Grant Program. The SSI/DCP regulations were rescinded when the program was repealed. However, the Title V statute retained a provision in its statement of purposes that funding be used to provide rehabilitative services for children under age 16 receiving SSI when they are not covered by Medicaid.

Despite the repeal of the categorical SSI/DCP requirements, state Title V programs continue to receive referrals from state disability determination agencies under the requirements of the Social Security Act. However, the capacity of programs to fulfill the mandate to provide rehabilitation services varies greatly among states.

Issues in Coordinating Different Responsibilities and Services During Transition Years

- Does the state vocational rehabilitation agency coordinate students' "individualized written rehabilitation program" [IWRP] with their individualized education program [IEP] to ensure that the full range of needed services are provided?

- Do state vocational rehabilitation agencies provide services to young adults as they prepare to leave school for post-secondary training or a job? What optional services does the state provide beyond the required ones? Are these optional services available to adolescents and young adults?

- Does the state vocational rehabilitation agency make any special effort to serve SSI-eligible adolescents and young adults?

- Do transition programs exist to increase interagency collaboration among health, employment, education, and vocational rehabilitation agencies at the state or local level? Are there opportunities for the local SSA offices to participate in these projects so they can share their expertise about SSI benefits and work incentives?

- Does the state Title V program provide assistance to adolescents and young adults as they begin preparing for transition to greater independence?

At age 16, or earlier if appropriate, a student's IEP must include a statement of needed transition services. It may explain the interagency responsibilities or the necessary linkages to ensure that the student receives the full range of services needed for a successful transition from school to higher education or work.

Students receiving special education services benefit from provisions in the IDEA Amendments of 1997 increasing the schools' responsibility for transition services. If an agency, other than the local school system, participates in the student's education and fails to provide the transition services described in the IEP, the school must reconvene the IEP team to identify alternative strategies to meet the student's transitional objectives. While this is a major improvement over previous policy, it must be monitored closely to ensure that schools fulfill their legal obligation.

See: www.ed.gov/offices/OCR/ocr504.html for Section 504 and Education.

Students with disabilities or chronic health conditions who are enrolled in a regular education program typically receive few, if any, supportive services through the school's special education program. However, these students may be entitled to receive related services including health services, transportation, adaptive equipment, and assistive technology through Section 504 of the Rehabilitation Act or the Americans with Disabilities Act [ADA]. Section 504 applies to any public or private school or college receiving any federal funding. The ADA applies to most schools and colleges, regardless of their funding. In general, Section 504 and the ADA require schools and colleges to provide students with "reasonable accommodation" allowing them to participate fully in school activities. Failure to do so can threaten the students' ability to make a successful transition to higher education or the job market.

See: www.ed.gov/offices/OSERS/RSA for the Rehabilitation Services Administration (RSA).

Each individual served by the State Vocational Rehabilitation [VR] agency has an "individualized written rehabilitation program" or IWRP. The IWRP is a written plan authorizing the services to be provided or funded by the State Vocational Rehabilitation agency that is reviewed annually so that any necessary revisions can be made. In theory, the planning process for the student's IEP and IWRP should be coordinated and some of the team members for each plan should be the same individuals.

See: Office of Special Education and Rehabilitation Services. RSA-Information Memorandum, 8/21/98 RSA-IM-98-23.

As State VR agencies begin their activities to implement the 1998 Amendments, new statutory requirements for State VR programs require the implementation of an Individualized Plan for Employment [IPE]. The IPE provisions delete some of the former content and process requirements for the IWRP and add new provisions to both enhance the collaborative relationships between the eligible individual and the qualified vocational rehabilitation counselor with respect to the development, implementation, and evaluation of the IPE and to support the exercise of informed choice of the individual in the selection of the IPE's employment outcome, specific services, service providers, and the methods to procure the services.

The IPE is identified in Section 102(b) of the Act.

IPE procedures and components are similar to the former IWRP requirements. State agencies will need to be careful in their implementation of the IPE provisions to ensure that they are faithfully expressed in the agencies' IPE policies, procedures, and practices.

Although SSI beneficiaries are automatically eligible for services from the State Vocational Rehabilitation [VR] office, this does not guarantee services. Families report that the provision of services is quite inconsistent within and among VR agencies. In theory, VRs could provide counseling or comprehensive vocational evaluations or help pay for college and other training programs for students when they graduate from high school.

The federal law governing state rehabilitation services is scheduled for reauthorization this year.

See: Presumptive Eligibility for SSDI Beneficiaries and SSI Recipients Section 102(a)(3)(A)(ii) Rehabilitation Act Ammendments of 1998 Title I of the Rehabilitation Act.

The Institute for Child Health Policy is following the reauthorization process and will keep readers informed about changes affecting the transition population. See http://www.ichp.edu/ssi for the latest information.

Issues in Improving Work Incentives

- What efforts are made to help young adults seek competitive employment and continue to receive their public health insurance?
- Do Social Security's existing work incentive programs address the specific needs of adolescents and young adults trying to make the transition from school to work?
- Do state vocational rehabilitation agencies address the specific needs of adolescents and young adults trying to make the transition from school to work?
- What efforts are made by the local school district and community organizations to provide adequate work opportunities for young people with disabilities?

Young people report that their greatest fear is losing their public health insurance if they start to work. Current insurance practices and limits on benefits generally eliminate private health insurance as an option for young adults who must instead continue to rely on their existing public health insurance.

Currently, people with disabilities who receive SSI generally have little choice in the providers of their vocational services. They are assigned to the state vocational rehabilitation agency that tends to favor people who have worked before. Individuals who do not receive the services they want have little choice but to purchase them from private vendors. Given the cost of private services, this is an option that few young adults and their families can afford. Young adults with disabilities need service providers outside the public program who know how to provide the special employment-seeking and rehabilitation services that they need to enter the work force for the first time. For example, they need to know the full range of assistive technology devices, job accommodations, and other types of supports that will help them obtain and keep a job. Some may also need assistance with daily living skills to prepare for their jobs or to learn how to live independently.

Individuals with serious disabilities face competition from others who are also trying to secure employment. Individuals who are leaving welfare, graduating from high school or college, or losing jobs from corporate restructuring and downsizing are all competing for a limited pool of jobs. This competition is particularly difficult for young people with disabilities who most likely have no work history and have more limited employment and/or social skills. Across the country, unfortunately, there is little effort to include students with disabilities and chronic conditions into existing state or local school-to-work programs. These programs, which are designed to provide career awareness activities, could help students with disabilities explore various work opportunities and possible careers.

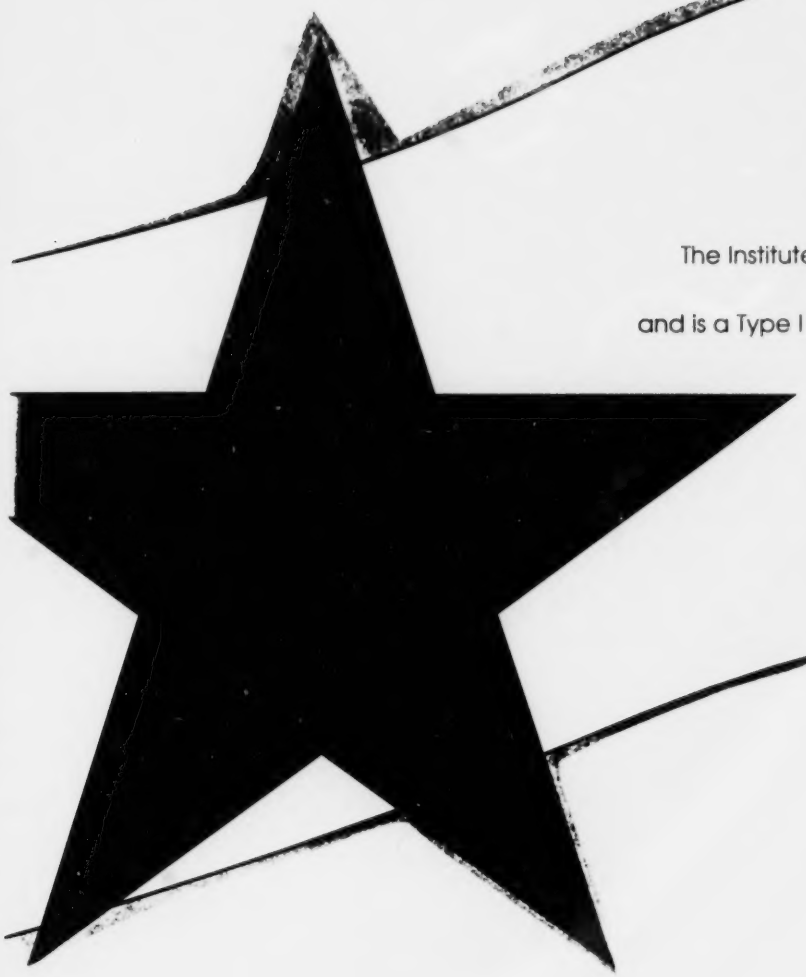
Conclusion

Putting together a successful transition plan for young people with disabilities is, sadly, complicated, confusing, and time-consuming for both service providers and families. As this important task is undertaken, it is critical to remember that transition planning must be specific for each student. Depending on the young person's age, disability, and family income, there are different "opportunity points" to pursue throughout the process. Transition planning is not an activity that is completed at any single point, but an evolving set of decisions that the entire family must continually revisit as they work with appropriate service providers. By working together, they can all help maximize the young person's future independence.

"We need to remember
that a lifetime on SSI
is a lifetime on the margins
— and likely in poverty.
We need to believe
that our young people deserve
— and can have —
a better life than that."

Susan Daniels,
Deputy Commissioner,
Disability and Income Security Programs
Social Security Administration

Notes



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